

References

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The Code of Codes: Scientific and Social Issues in the Human Genome Project. Edited by Daniel J. Kevles and Leroy Hood. Cambridge and London: Harvard University Press, 1992. Pp. 397. \$29.95.

The U.S. Human Genome Project (HGP) may be the first coordinated scientific endeavor to formally address the social consequences of its scientific research program. From its beginning, the HGP has reserved approximately 3%-5% of the overall scientific budget for study of the ethical, social, and legal implications of the use of the information that the project's research will generate. A total of approximately \$5.1 million, about 5% of the total HGP budget, was directed toward these studies in fiscal year 1992 (E. Langfelder, National Center for Human Genome Research, personal communication). This book reflects the interdisciplinary approach of the HGP, presenting both scientific perspectives and commentary on social and ethical issues. It is notable that the content of this book is more heavily weighted toward consideration of the latter than is the HGP itself; fully two-thirds of the book consists of essays with historical and ethical themes. This diverse collection affords an opportunity to compare and contrast the thoughts of individuals who are considering the implications of this genetic research from very different disciplines and perspectives.

The scientific essays, subtitled "Genetics, Technology and Medicine" and sandwiched between "History and Politics" and "Ethics, Law and Society," offer predictions about the impact of HGP research on biology and medicine, from leading scientists in the field. The long-range goals of the project are to develop a detailed map of the human genome and perhaps ultimately to determine the complete sequence of the estimated 3 billion bases (although James Watson now suggests that the project probably will be considered finished when 98% of the sequence of the functional regions is obtained). Technology development is key to achieving these goals. As Leroy Hood states, "the human genome project is the first major biological initiative that takes the development

of technologies as one of its major objectives" (p. 136). Thus, as expected, some of these essays are highly technical in content. This emphasis on the technical aspects of gene mapping and sequencing may seem daunting to some lay readers, although efforts have been made to simplify the language and to supplement the text with figures and diagrams illustrating the procedures and principles.

According to the scientific contributors, the enormous quantity of information about the human genome that the project will generate, coupled with this focus on technology development, will result in "a dramatic change," "a striking revolution" in biology and medicine (pp. 112, 136). Walter Gilbert envisions a paradigm shift in biology, toward an increasingly theoretical reflection on the meaning and function of gene sequences. The most immediate effect on medicine, in addition to the identifying of genes implicated in rare genetic disorders, will arise as genetic factors that contribute to common conditions such as cancer, cardiovascular disease, and schizophrenia are determined. The identification of genes or genetic factors that contribute to disease processes precedes, often by several years, the ability to provide improved treatment or to alter the course of disease on the basis of this knowledge. Thus the immediate impact of the generation of this information is predicted to reside in the area of diagnostic genetic testing and screening. Charles Cantor expects that, in 15 years, multiplex testing for 100-1,000 of the most common genetic disorders and predispositions will be possible for fetuses, newborns, and adults. Hood offers a vision similar to Cantor's and, more optimistic about accompanying advances in therapeutics, suggests that "medicine will move from a reactive mode (curing patients already sick) to a preventive mode (keeping people well)" (p. 158).

Several contributors to the ethics section of the book address the implications of an increased use of genetic information in the clinical setting. Henry Greeley outlines the effects of an improved ability to predict individual health on current modes of health-care financing. Ruth Schwartz Cowan combines an analysis of the history of technology with a feminist approach, to explore some ethical issues surrounding prenatal diagnosis. Nancy Wexler, chair of the Ethical, Legal and Social Implications Working Group of the HGP, provides a detailed picture of the search for the Huntington disease gene and the considerations associated with presymptomatic testing and diagnosis.

The remaining essays address the use of genetic information outside the health-care environment and the implications of knowledge of genetic information about human traits unrelated to disease. For example, Dorothy Nelkin questions societal definitions of normalcy and abnormality, focusing on how these definitions are shaped by the availability and use of biological tests and on how such tests are used to categorize individuals. To Nelkin, the pervasiveness of sociobiological assumptions, and the associated "social power of genetic information," raises the possibility of creating a "ge-

netic underclass" of individuals who are uninsurable, unemployable, and/or uneducable (p. 190).

The belief that genes "make us what we are" and "define our possibilities and limitations as members of the species" is analyzed by Evelyn Fox Keller (pp. vii, 281). She traces the shifting nature-nurture debate and the cultural context within which that debate occurs and critically examines the construction and meaning of the concept of genetic disease. The specter of eugenics, first described in historical detail in the opening chapter by Daniel Kevles, reappears here as the possibility of a "eugenics of normalcy" (p. 299).

Throughout the book, contributors emphasize the importance of both professional and public deliberations on these complex issues as necessary to their resolution. However, although the editors briefly mention disability groups in their last chapter, no members of "the public" are represented in this collection. Increasingly, there is a need to appreciate the experiences, perspectives, and insights of those most affected by the use and availability of genetic information and actively to develop ways to incorporate such experiences into general and policy discussions.

In addition, the need for public education in genetics and molecular biology is noted by many contributors. The editors also recognize the need for increased professional awareness of the ethical implications of genetic research. In their final chapter, they state that education in the social and ethical implications of genetic research should become a part of the professional training of all biologists. Certainly, interdisciplinary research efforts have become an integral part of the HGP. Consider the recent announcement of the newly awarded genome center at the University of Iowa. The three principle goals of this ninth genome center are (1) to develop a high-resolution, microsatellite-based genetic map of the human genome, (2) to address ethical, legal, and social issues (specifically, discrimination and access to health insurance, quality-control issues, and confidentiality concerns) raised by genetic research, and (3) to teach high school science teachers about genetics and the HGP (Ninth NIH Genome Center Established at University of Iowa, 1992). It is hoped that such a combined approach will prove effective in identifying, understanding, and resolving the numerous and complex social, legal, and ethical issues raised by HGP research.

SHARON J. DURFY

Department of Medical History and Ethics
University of Washington
Seattle

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Attitudes to Genetic Engineering: Japanese and International Comparisons. By Darryl Macer. Christchurch, New Zealand: Eubios Ethics Institute, 1992. Pp. 328. \$35.00.

Darryl Macer provides us with feedback from voices rarely heard among philosophers, biologists, physicians, theologians, and others who speak on genetic engineering: the general public. From the conviction that as genetics expands, it will revolutionize matters of medicine, health, and food, Macer argues that we must take time out to register the perceptions, fears, and hopes of the greater community. This is not an idle academic move; rather, Macer believes—and the data back his hunch—that the public progressively has a sense of being disenfranchised as the scientific community advances into the brave new world. Since, frequently, the scientific community does not engage the greater populace in deliberations about its ways of proceeding, suspicion about the scientific community grows. Macer sees his study as providing more than a simple warning, however; by informing the public through the media, the scientific community has greater opportunity for winning consensual support for its projects. Beneath the first layer of suspicion there resides a core of great expectations, Macer's report finds, among the public at large.

Macer's study engages the Japanese population. In fact, the 328 pages are actually a 164-page English book with an exact Japanese translation of equal length attached. The study reports results from a questionnaire that took more than 20 min to complete and that was sent in 1991 to 5,030 different persons, from whom about 1,700 responses were received. Two different sample populations were targeted. A public sample group queried a broad working population, though nearly 50% of the respondents were either housewives or company employees. A specific sample population was made up of high school biology teachers, scientists, students, and the University of Tsukuba staff where the survey originated. The survey claims to be the most extensive of its kind.

When the returns are analyzed, the survey shows that the Japanese are considerably informed on a number of scientific developments, such as genetics, fiber optics, silicon chips, and superconductors. On occasion, Macer compares his findings with those of more limited surveys from other countries, especially New Zealand and the United States. For instance, in areas related to public perceptions of science and technology, despite New Zealanders' rather healthy confidence in science, the Japanese perceive even greater benefits from science.

The Japanese are considerably enthusiastic about genetics. The various samples highlight nearly uniform acceptability of genetic manipulation of different organisms, from plants to